Child-headed households in Rakai District, Uganda: a mixed-methods study

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Objective: An important but neglected consequence of the AIDS pandemic that continues across sub-Saharan Africa is the phenomenon of child-headed households (CHH). This study aims to describe the challenges to health and well-being for young people living in child-headed households.
Methods: A mixed-methods research approach linked common themes using qualitative and quantitative instruments to provide a broad picture of the location and challenges of CHH in Kabira, Kyotera and Kamuganja in the Rakai District of southern Uganda. Local knowledge was used to locate CHH.
Results: 163 children living in 40 CHH were traced: 42.5% of the household heads were double orphans caring for younger siblings, and 43% were also caring for chronically ill or disabled grandparents who were economically unproductive and largely dependent on the eldest child for survival. It was found that those heading households were more likely not to attend school than children living at home with a parent. Their immediate needs ranged from food and shelter to health-care and education. Fear was a major theme: 38% of those interviewed reported fear of 'violence'. Children as young as 13 were responsible for navigating through complex decision-making processes from everyday basic necessities to decisions on the health care of younger siblings and grandparents.
Conclusion: Children and young people living in CHH are a largely invisible and highly vulnerable population. Clear, officially accepted definitions of CHH are a first step in recognising this vulnerable group for whom safeguards will be necessary as social work develops in lower- and middle-income countries (LMICs). The precise numbers of CHH are unknown and further examination of this undocumented group is needed.

Keywords: Child-headed families, Uganda, HIV/AIDS

Abbreviations

CHH, child-headed households; NGO, non-governmental organisation; LMICs, lower- and middle-income countries.

Introduction

It is estimated that 25 million children in sub-Saharan Africa have been orphaned by AIDS, and this is expected to reach 40 million by 2020.[1,2] The 2013 Population Report for Uganda estimated that 14% of children under 18 years of age were orphans, half of these owing to HIV/AIDS.[3] Several studies have examined the problems faced by orphans in Uganda.[4,5] It has been argued that few fall through the safety net provided by the familial network.[6] Others provide evidence that many orphans leave for urban centres, departing from communities where resources are over-stretched. Many end up as street children. Some, especially girls, are lured into early marriages and others can be exposed to sexual or labouring exploitation. Increasingly, it is reported that more orphans choose to remain in their communities to run the household.[7] Child-headed households (CHH) have been referred to as a new 'coping mechanism' in the AIDS pandemic.[8]

The first reports of large numbers of child-headed families appeared in the early '90s in Uganda and later in Tanzania, Zambia and Zimbabwe where the HIV/AIDS epidemic began to develop. Today, the problem stretches widely across sub-Saharan Africa and yet no extensive study has ever documented the problems and challenges faced by child-headed

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families. Little is known of the national reality in Uganda.

CHH are frequently relegated to generalisation as orphan populations, thus limiting precise information on the struggles and challenges that they uniquely face.[9] Definitions of CHH vary: there is no consistent or solid definition. A study from Zimbabwe defined a CHH as one in which both parents have died in the preceding 5 years but the children are supported by relatives.[10] The authors report that 18.3% of households included orphans, of whom half were also estimated to have lost one or both parents as a result of HIV infection.[11] CHH have also been defined as households in which all occupants are younger than 18 years.[12] Others extend the definition to include bedridden parents and the elderly.[13]

It is frequently assumed that households headed by children receive regular support, be it from the extended family, non-governmental organisations or governmental agencies.[14] Prevailing socio-cultural values in Uganda support orphaned children being cared for within extended families. Institutionalised care has not been popular.[15] It should be emphasised that in nearly every sub-Saharan African country the extended family remains the predominant caring unit. Nevertheless, the emergence of CHH demands recognition, perhaps as a subcategory of 'orphan', indicating that the elasticity of the family safety-net has and continues to be stretched to its limits and children are frequently bearing awesome familial responsibilities.

Methods

The study was conducted in July and August 2010 in the Rakai District of Uganda. Uganda is divided into districts with four administrative regions: Northern, Eastern, Central and Western. Our study was based in three areas of the Central region, the Kingdom of Buganda. The 5.5 million Buganda (singular Muganda) are the largest ethnic group in Uganda, 16.9% of the population. Kabira, Kyotera and Kamuganja are located in the Rakai District and were chosen as survey sites because of the primary author's knowledge of the area. The first cases of HIV/AIDS in Uganda were reported in 1982 in the Rakai District, an area that has subsequently been identified as one of the world's most severely affected by the HIV/AIDS pandemic. The population of Kyotera is estimated to be 9000 and it is the major city south of Masaka, the chief town of the Masaka District.[16] Kabira and Kamuganja are sub-counties. A convenience sample of CHHs was taken, based on the knowledge of two local teachers and a doctor in the community. Snowball sampling was used to identify undocumented CHH known to people within the community. They were then invited to participate in the study.

For the purpose of this study, CHH was predefined as any family headed by a child of 18 years or younger. The child is the primary caregiver, left on his/her own to sustain the family unit and to provide materially and emotionally for younger brothers and sisters and/or chronically ill parents or grandparents. The eldest child in the house was the main respondent and our findings present their views and experiences. An 11-page, semi-structured household questionnaire was piloted. After obtaining verbal consent, CHH were interviewed in Luganda and/or English, depending on the language they chose to speak. Trained translators were present throughout the interview. The questionnaire used closed and open questions to ascertain quantitative and more narrative accounts of the children and young people's circumstances. Some heads of households wrote autobiographical narratives and drew pictures of their experiences, illustrating a number of challenges that they face.

Key-informant interviews were held with local community leaders and NGOs working in the area. They focused on involvement and understanding of the complex nature of CHH. Every attempt was made to engage a variety of stakeholders, including those with direct involvement with CHH, government officials and local community group leaders. Focus group discussions took place in Luganda, the local language, with local community leaders.

All interviews and focus group discussion were transcribed to text.

Data analysis

All data were stored in the lead researcher's laptop and entries were password-protected. After performing quality assurance checks, data were entered into an electronic spreadsheet (Microsoft Excel 2008, version 12.2.7). Simple quantitative descriptive analysis was performed directly using Excel. Qualitative analysis consisted of investigators independently reading and re-reading the narratives to identify prominent and recurring themes. Using an open-coding methodology, themes were chosen based on the number of times the issues were raised in the self-reported narratives. Investigators agreed on the themes finally identified. Institutional Review Board approval was granted prior to the study by Harvard University Committee on the Use of Human Subjects in Research. Local government permission to conduct the study was granted by the regional medical director.

Results

Population characteristics

A total of 40 CHH were interviewed with 163 children living in them. The respondents were predominately male (60%). Of those interviewed, 55% were aged 11–15 years with a range of 6–18; 25

children were under 16 years of age. The majority of CHH self-identified as being Muganda (82.5%). A significant number identified themselves as Rwandese, most specifically in the Kamuganja region (17.5%).

The majority of respondents, 42.5%, were recorded as double orphans caring for younger siblings; 43% were caring for weak, chronically ill or disabled grandparents who were economically unproductive and largely dependent on the eldest child for survival. In over half of the households, children became heads of the home following the death of a parent or the death of both parents, with 18% stating AIDS as the cause of death. One respondent from a child-headed household commented: 'When my father and mother died of AIDS we had a very terrible situation. There was no food at home after school anymore. No house to stay in.' When asked how long they had been the head of the household, 43% reported 4–6 years, 30% 1–3 years, 20% >8 years, and 17% could not provide an answer.

Education, work and sexual assault

A significant number of respondents, 37.5%, had received no education. For those who were in primary school, 18% indicated a system whereby they were forced to alternate between time at home and at school, and 30% were regularly sent home for not having the appropriate clothing or equipment. The Central Region reported average primary school attendance of 79.6%.[17]

Employment ranged from agriculture to the sex industry. The majority (58%) reported 'digging', either agricultural labour in the fields or sorting through rubbish, as the source of their livelihood.

Living conditions

The mean number of occupants per household was four, but there were as many as seven in one house. 45% of respondents resided in houses described as 'semi-permanent brick or mud', 27% lived in a 'mud house without iron sheets' and 7% had housing identified as a 'temporary grass hut'. 28% of respondents did not have a mattress, 15% of households were reported as being dangerously infested with animals and/or insects, and in 20% of homes animals were living in the room where children slept. Toilet facilities were minimal: 35% of respondents had no lavatory in the home and used the bush, 45% shared a lavatory with neighbours and 53% used a pit latrine.

When asked about access to water, 72.5% obtained water from a dug well, 40% of whom described the journey to the well as unsafe, and 28% reported that the average time taken to reach a water source was more than 50 minutes.

Health

When asked if they presently felt unwell, 65% responded that they did. In terms of where they attended for illness, 50% identified a government clinic, 27.5% traditional methods and 22.5% said they had nowhere to go for medical attention. Of the 50% who did have access to a government health clinic, 25% claimed that the clinic frequently had no medication and/or they received no help there. Health problems included malaria (60%), stomach pain (57.5%), fatigue (55%), headache (50.0%), back and neck pain (47.5%), diarrhoea (22.5%), fever (20%), toothache (12.5%), ear infection (7.5%) and seizures (2.5%). The Uganda Demographic and Health Survey conducted in 2011 reported a prevalence of all children with diarrhoea in the Central Region as 22.3%. Fever in the 2 weeks before the survey was reported by 42.4%, and 86.9% of those were taken to a health provider or pharmacy; 63.4% took antimalarial medication.[18]

Nationwide, it has been reported that 72% of people in rural areas own at least one mosquito net and 42% under the age of 5 in rural areas are reported to sleep under an insecticide-treated net in rural areas.[17] In this CHH study population, only 20% had mosquito nets and three were not using the mosquito nets because they did not have the means to hang them.

Reported responsibilities and challenges

For the eldest child, availability of bedding and a sleeping mat were reported most frequently when asked what worried or challenged them the most (77.5%). Food and shoes were also listed as high priorities. A significant number, 62.5%, described inability to pay school fees or for medications as one of the greatest challenges they faced.

Thematic Analysis

Security and fear

Fear was a major theme: 50% expressed fear of their possessions being taken from the house while they attended school, 48% reported fear in having to travel to a well to fetch water, and 38% were afraid of 'violence'. The vulnerability of these children was perhaps most evident in the violence to which they were subjected. Many received 'beatings' for being late at school, often a result of tending to the needs of younger siblings. One described being beaten unconscious by his employer. This specific child head of a household was providing for a grandmother who was chronically ill and for a younger sister. Another stated payment of 5000UGS ($US2.2) for 4 days work of digging. Another described domestic work that involved 'cleaning faeces from clothes.' Over half of those who were working recalled not receiving payment for work. A number of participants were leaving children as young as 6 years in charge of the household while they went to work.

Of the 16 girls interviewed, five stated that they had been raped and another reported attempted rape.

One girl recalled: 'at our parents' funeral, relatives came and stole possessions … I am in and out of school, caring for four siblings. …We live in a collapsing mud hut…. Our parents died to AIDS. I have been beaten on the way to the well. Men have tried to rape four times.' One perpetrator was a family member and three others attacked while the child travelled to a well. In a setting in which resources are depleted, CHH are frequently forced to resort to desperate measures to survive. Six of the female CHHs reported prostitution as a means of supporting the family. One reported receiving 5000UGS ($US1.87) for an act of prostitution, and used the money to help pay for school fees and school supplies so that they were not asked to leave school. UNICEF have concluded that girls in Uganda without parental care have been found to engage earlier in sexual activity than those whose parents are alive.[15] Such sexual exploitation increases the risk of young girls contracting HIV, which was a fear expressed by all the female participants. A sense of 'shame' was also associated with those engaging in prostitution. In one instance, a female respondent attempted to protect herself and her younger sister from the shame that she felt by requesting that her sister leave the room before describing how she earned money for the home: 'Men break into our house and ask for love. They touch me and persuade me to have sex. I also go to one man [and] get paid 10,000UGS ($US3.74), sometimes only 5000 ($US1.87). I go to get money. I do not want my sister to know. I fear pregnancy and disease. I need money to buy salt, fuel, soap and food. I do it once a week. I think I am not pregnant.'

Support-seeking

As one respondent reported, 'After our parents died we had no support. We lived alone and were fearful. We had no equipment in the house to cook and started getting problems at school. We had no school fees. We had to drop out of school.' Studies which have relied merely on NGO information to locate child-headed families have perhaps neglected to account for CHHs without NGO support. The most common identified theme in the qualitative analysis, reported in 85% of interviews, was that of support. When asked if they had somewhere to go for support, 82% of the children answered that they had nowhere to go. Some reported breakdown of extended kin support: 'My mother was sick and died, and father died. Our first house collapsed. There was our uncle's house but he did not want us to live there so we would sneak in when we could. Uncle chased us last week. We live in a collapsed house.'

Key-informant interviews revealed that the phenomenon of CHH was known, but, in the areas in which we were searching, the precise locations and specific needs were previously unknown. Key-informant interviews with local officials reported that many adolescent girls leave home to work in local towns or travel to the capital city, Kampala.

Educational needs

All respondents expressed a desire to attend school. Activities and demands of the home had resulted in a high drop-out rate. Sometimes the eldest sibling reported passing over the opportunity to attend school in favour of a younger sibling. Uganda has the government-sponsored Universal Primary Education (UPE) initiative which aims to offer tuition-free primary schooling for all children to primary seven. In practice, without the means to purchase school equipment – uniforms, books, paper, pens, pencils – the majority of CHH children fall through the net in a system that fails to fulfil its promises. Humiliation associated with not being properly equipped for school was frequently reported. Of the CHH who we interviewed, 37.5% were unable to access any education. The UPE programme does not offer concessions for children with special needs such as those who have to tend to relatives and siblings: 'After they died we had nothing at home, we did not even have paraffin, no food – nothing. So we started picking some coffee and sold it for 100 shillings and salt …. I did not go to school today because I had to cook food for these ones.'

Health needs

Children repeatedly reported problems in accessing medical services. In principle, government clinics in Uganda are accessible to all, but stigmatisation and a lack of money and transport prevent many from receiving treatment. One child recalled being arrested by police officers because of his inability to pay for the medication that he had received for his sick grandmother. Many considered treatment of sickness as a last resort, most likely because of other financial concerns within the home which demanded priority. Respondents frequently resorted to traditional medicines.

Discussion

Principal findings

The typical CHH in these areas of Uganda is male, unlike reports of female-headed households elsewhere.[19] Our quantitative survey and qualitative interviews both highlighted the pervasive and frequent nature of sexual assaults on this population (especially girls). Many CHH are not being supported at all and are vulnerable to exploitation and violence. A high number of these children are surviving in sub-standard living conditions. The findings in this study confirm that the psychosocial needs of CHH are complex and multi-faceted. Children in such conditions are not only

deprived of their childhood but are inundated by social and economic challenges. Economic hardship leads them to look for means of subsistence which increase their vulnerability to HIV infection, disease, child labour and sex work. A sense of rejection was expressed by 25% of cases. Rejection was closely linked to a feeling of being stigmatised because of their status as CHH, without a parent in the family home.[20] A sub-population of Rwandese migrants in Kamuganja reported heightened rejection on account of their ethnicity.

Child-headed households are the result of a rational and conscious decision by children to maintain the surviving family unit. The desire for the family unit to remain together was reported in every interview, a pattern that has been documented elsewhere in the orphan literature for sub-Saharan African.[21] The eldest child had taken on either a maternal or paternal role to support the family. These child carers' daily lives were focused on family unity and survival. Often they reported being faced by complex scenarios that demanded decisions: which sibling would attend school? For which sibling could they seek malaria treatment? Some were forced to consider prostitution as the only viable option in order to feed the family. Issues of property and emotional attachment to the family land often informed the very foundation for the establishment of the CHH. Much mistrust of relatives and their desire to 'adopt' them or claim ownership of their property was apparent.[22] A number of those interviewed expressed concern at not legally owning their homes as there were no title deeds. Our report found that the primary source of physical and emotional support was that of other siblings in the home.[23]

Organisations frequently had policies addressing the issues of orphans and vulnerable children, but CHH were not considered as a specific and unique category. One NGO had supported a number of the children in constructing their houses but the organisation was no longer present. Many houses were in urgent need of maintenance. In contrast with other recent studies, this report found formal support to be irregular and at times entirely absent. Furthermore, that various NGOs had supported CHH in the past meant that the community had reduced their assistance to these families. Thus, when an NGO withdrew their sponsorship, the families had no form of aid.

Strengths and Limitations of the Study

Owing to resource and time constraints, this project was of brief duration, which limited the study sample size and precluded the collection of control data from adult-headed households. Where possible, local Ugandan demographic health survey estimates for the Central Region are provided for comparison. It is possible that translation might have introduced error into the narratives. However, to limit such errors, a local translator helped provide cultural background and context. When asked how long they had been identified as child-headed households, many were unable to give specific responses so these figures have to be viewed cautiously. In addition the majority of children were unable to state the cause of their parent's death, and thus the figure of 18% having died of AIDS is likely to be an under-estimate. In the focus group portion of the project, as with all qualitative research, the role of the moderator is a source of bias. In an attempt to mitigate this, facilitators were trained in focus-group methods.

Generalisability of Findings

There is no widely agreed definition of CHH (see above). That CHH receive regular support is a sentiment frequently echoed throughout the literature.[14] Conversely, this study found formal support to be irregular and often entirely absent. Furthermore, the fact that various NGOs had supported CHH in the past had led the community to withdraw assistance from these families. Thus, when an NGO withdrew sponsorship, the families received no help.

This study suggests that in this area of Uganda, CHH are largely invisible to the authorities and do not receive regular support.

Implications

In environments of conflict, disease and natural disasters, children can be scattered and the traditional family unit fragmented or destroyed. As the number of orphaned children multiplies, it is likely that CHHs will become less transient and more common.

This study found that the primary source of physical and emotional assistance was that of other siblings.[23] Much mistrust of relatives and their desire to 'adopt' or claim ownership of their property was apparent.[22] Issues of property and emotional attachment to the family land often informed the very foundation for the establishment of the CHH. Attachment to the family land could be viewed as displaced attachment behaviour following parental loss. A number of those interviewed expressed concern at not legally owning their homes in the absence of title deeds. Organisations frequently had policies addressing the issues of orphans and vulnerable children but not of CHH as a specific and unique category.

Many reports have concluded that CHH are capable of running their households, but the respondents we interviewed about their role as CHH were burdened by extreme stress and the responsibility. Families were large, the average number in the households being four, higher than the official mean

number of 2.8 reported for CHH.[24] The eldest child had embraced either maternal or paternal roles to support the family. Often they reported being faced with complex scenarios that demanded decisions. Studies asserting that these children are adaptable and resilient are misleading and give the impression that their circumstances are acceptable.

Recommendations

There is a pressing need to identify interested adult support in the surrounding community, acceptable to the CHH. Guardianship is recognised under the terms of the Children Act in Ugandan law but is rarely applied in such dispossessed situations. This could be a role for respected community elders.

Conclusion

Much has been said about the plight of orphaned children in sub-Saharan Africa. This is as it should be, but the need for action is even more compelling for households headed by children who are deprived of their first line of protection – their parents. This study underscores the complexity of the psychosocial needs of CHH. The interaction of loss, emotional trauma and quasi-parental responsibility results in severe stress at a vulnerable age and, for some, a lack of any kind of vision for their future lives. Within the category of orphans and vulnerable children, CHH have unique needs and challenges. Further study of this under-reported population is needed with particular consideration of what sustainable means of support could be developed to alleviate the psychosocial stress they currently suffer and how their educational prospects could be improved.

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